

# RESOURCES

## State Resources

### [Department of Elementary and Secondary Education](#)

P. O. Box 480  
Jefferson City, MO 65102  
Phone: 573-751-4212

### [First Steps](#)

First Steps offers coordinated services and assistance to young children with special needs and their families. First Steps is designed for children, birth to age 3, who have delayed development or diagnosed conditions that are associated with development disabilities. Families can contact their county First Steps Office for more information by calling toll free: 1-866-583-2392

### [Department of Health and Senior Services](#)

<http://www.dhss.mo.gov/AskUs.html>

P. O. Box 570  
Jefferson City, MO 65102-0570  
Phone: 573-751-6400

### [Alcohol, Tobacco, and Other Drug Prevention & Awareness](#)

To reduce the risk of alcohol, tobacco, and other drug-exposed pregnancies, DHSS provides education for health care professionals to promote early identification, intervention and referral of at-risk women and children. Service coordination is also available to individuals up to age 20 who were prenatally exposed to alcohol and/or controlled substances and substantiated by the Department of Social Services to be at risk for child abuse/neglect.

### [Alternatives to Abortion](#)

The Alternatives to Abortion Program is for the purpose of funding alternatives to abortion services for women at or below 200% of the Federal Poverty Level. It consists of services or counseling offered to a pregnant woman and continuing for one year thereafter, to assist her in carrying her unborn child to term instead of having an abortion and to assist her in caring for her dependent child or placing her child for adoption. Services include but are not limited to the following: prenatal care; medical and mental health care; parenting skills; drug and alcohol testing and treatment; child care; newborn or infant care; housing; utilities; educational services; food, clothing and supplies related to pregnancy, newborn care, and parenting; adoption assistance; job training and placement;

establishing and promoting responsible paternity; ultrasound services; case management; domestic abuse protection; and transportation.

For a list of providers go to:

<http://www.dhss.mo.gov/AlternativesToAbortion/Providers.doc>

#### Children with Special Health Care Needs (CSHCN) Program

The CSHCN Program provides assistance to children birth to age 21 who meet financial and medical eligibility guidelines. This program focuses on early identification of children with special needs; funding for preventive, diagnostic and treatment services; and provision of service coordination activities for families. Service coordination is provided through 13 contracts and by Special Health Care Needs staff located in regional offices throughout the state.

Participants must meet both medical and financial eligibility guidelines and reside in Missouri.

#### Healthy Children and Youth (HCY)

The HCY Administrative Case Management Program assists families in meeting their child's needs to function at an optimal level. Assistance is provided for: access to screening services; follow-up on referrals to additional medical providers; establishment of a medical home; service plan development; and follow-through on the treatment plan.

Treatment is determined by the primary care provider. As a part of the Administrative Case Management role, the Special Health Care Needs staff assists in securing the following services: home health services, private duty nursing, personal care service, advanced personal care services, and HCY Case Management through Local Public Health Agencies.

This program is available to all MO HealthNet eligible children (birth to age 21) residing in Missouri who are in need of medically necessary services from MO HealthNet providers.

#### Family Partnership

<http://www.dhss.mo.gov/FamilyPartnership/>

<http://www.dhss.mo.gov/FamilyPartnership/ContactUs.html>

The Family Partnership was formed by Special Health Care Needs (SHCN) to enhance the relationship between SHCN and the families they serve. It provides support and information to these families and an opportunity for families of individuals with special health care needs to connect with each other.

The Family Partnership members include individuals with special health care needs, as well as, parents, family members or legal guardians. The Partnership has three professional Family Partners who share responsibility for each of SHCN's service areas. The Family Partners are parents of special needs individuals served by SHCN. In addition to providing information and resources to local members, they serve as the Partnership's contact person for their designated areas. They plan, schedule, and facilitate the Family Partnership meetings.

#### TEL-LINK

Get Connected to Better Health

Phone: 800-TEL-LINK or 800-835-5465

TEL-LINK is the Missouri Department of Health and Senior Services toll-free information and referral line for maternal and child health care. The purpose of TEL-LINK is to confidentially provide information and referrals to Missouri residents concerning a wide range of health services offered by the state. The operators can immediately connect you with community services that are available for you and your family. TEL-LINK is answered weekdays from 8 a.m. to 5 p.m. Central Time. Recorded messages are taken after 5 p.m. on weekdays and throughout the day and night on weekends and state holidays. Your call will be returned during normal business hours.

#### [Department of Mental Health](#)

Division of Mental Retardation and Developmental Disabilities

1706 East Elm St

Jefferson City, MO 65102

Phone: 800-364-9687

#### Network of Care

[http://missouri.networkofcare.org/home\\_state.cfm?stateid=30](http://missouri.networkofcare.org/home_state.cfm?stateid=30)

Network of Care for Mental Health/Behavioral and Developmental Disabilities

Network of Care is a highly interactive, single information place where consumers, community-based organizations and municipal government workers all can go to easily access a wide variety of important information. The resources in this "virtual community" include a fast, comprehensive Service Directory; links to pertinent Web sites from across the nation; a comprehensive, easy-to-use Library; a political advocacy tool; community message boards; and many others.

### [Sarah Jian Lopez Medicaid Waiver](#)

The Sarah Jian Lopez Medicaid Waiver allows access to funding for appropriate care and support for children with developmental disabilities so they may continue living at home with their families.

Medicaid guidelines require parental income and resources be considered for children who live at home, but allow such income and resources to be disregarded for children who live out of the home, in an institution, a group home, or in other residential settings. The waiver allows parental income and resources to be disregarded for permanently and totally disabled children living at home who otherwise would require services at an institution. Contact the Department of Mental Health about eligibility guidelines.

### [Department of Social Services](#)

Broadway Office Building  
P. O. Box 1527  
Jefferson City, MO 65102-1527  
Phone: 800-735-2960

### [Adoption Home Page](#)

### [Rehabilitation Services for the Blind](#)

615 Howerton Court  
P. O. Box 2320  
Jefferson City, MO 65102-2320  
Phone: 800-592-6004

Rehabilitation Services for the Blind (RSB) is a state agency that has staff that specialize in providing free services to blind or visually impaired children ages 0-14 and their families.

### [MC+ for Children](#)

Phone: 888-275-5908 (Translation services available)

MC+ for Kids, part of the federal Children's Health Insurance Program, is a health insurance program for uninsured children of low-income families who do not have access to affordable health insurance.

Uninsured children, ages birth to 19, whose gross family income is up to 300% of the federal poverty level are eligible.

## **GENERAL GENETICS CLINICS**

### [University of Missouri](#)

Columbia, MO

Phone: 573-882-6991

Provides comprehensive genetic services.

### [Children's Mercy Hospital](#)

Kansas City, MO

Phone: 816-234-3771

Provides comprehensive genetic services.

Saint Louis University School of Medicine

### [SLU Medical Genetics](#)

SSM Cardinal Glennon Children's Medical Center

St. Louis, MO

Phone: 314-577-5639

Provides comprehensive genetic services.

### [Washington University School of Medicine](#)

St. Louis Children's Hospital

St. Louis, MO

Phone: 314-454-6093

Provides comprehensive genetic services.

## **NEUROGENETICS-GENETICIST**

Washington University School of Medicine

St. Louis Children's Hospital

St. Louis, MO

Phone: 314-454-6093

Provides comprehensive genetic services with a neurologist.

## **GENERAL GENETICS OUTREACH CLINICS**

### [Kirksville Regional Center Genetics Outreach \(University of Missouri\)](#)

Kirksville, MO

Phone: 573-884-6735

Provides comprehensive genetic services every other month.

### [Springfield Outreach Genetics Clinic \(University of Missouri\)](#)

Springfield, MO

Phone: 417-820-9839

Provides comprehensive genetic services once a month.

### [Versailles Metabolic Outreach Clinic \(University of Missouri\)](#)

Versailles, MO

Phone: 573-884-5192

Provides comprehensive metabolic genetic services.

### [Children's Mercy Hospital Genetics Outreach Clinic](#)

Freeman Hospital

Joplin, MO

Phone: 866-424-3771

Provides comprehensive genetic services.

Shriner's Hospital (Washington University School of Medicine)

Shriner's Hospital

St. Louis, MO

Provides comprehensive genetics services once or twice a month.

Cape Girardeau Department of Health

(Saint Louis University School of Medicine)

St. Francis Medical Center

Cape Girardeau, MO

Provides comprehensive genetic services.

## **GENERAL GENETICS TELEHEALTH CLINICS LOCATIONS**

University of Missouri  
Columbia, MO  
Phone: 417-277-5619

Southern Missouri Community Health Center Telehealth Clinic  
West Plains, MO

Cox South Medical Center Telehealth Clinic Cox South Medical Center,  
Turner Center, Springfield, MO

Poplar Bluff Regional Medical Center Telehealth Clinic  
Poplar Bluff, MO

Southern Missouri Ozarks Health Center Ava Telehealth Clinic  
Ava, MO

Missouri Rehabilitation Center Mt. Vernon Telehealth Clinic  
Mount Vernon, MO

Jordan Valley Community Health Center Telehealth Clinic  
Springfield, MO

## **MATERNAL FETAL MEDICINE/PRENATAL GENETICS**

### [Center for Maternal Fetal Care, Women's Health Associates](#)

1601 East Broadway, Suite 330  
Columbia, MO 65201  
Phone: 573-443-8796

Provides prenatal and preconception consultations, genetic counseling, ultrasound, first and second trimester screening, amniocentesis, and high-risk pregnancy care.

### [Center for Women's Health and Fetal Health](#)

Washington University School of Medicine  
Missouri Baptist Hospital  
St. Louis, MO  
Phone: 314-996-6024

Provides diagnosis, treatment, management, and genetic counseling services for preconceptual and pregnant women.

[Children's Mercy Prenatal Clinic](#)

Kansas City, MO

Phone: 816-234-3771

Fetal Evaluation and Treatment Unit  
Saint Louis University School of Medicine

SSM St. Mary's Health Center

St. Louis, MO

Phone: 314-768-8730

Provides diagnosis, treatment, management, and genetic counseling services for preconceptual and pregnant women.

Regional Perinatal Center

1000 E Primrose, #360

Turner Center

Springfield, MO 65807

Phone: 417-269-4037

Provides high-risk obstetrics including first trimester and sequential screening, and prenatal diagnosis.

St. John's Maternal Fetal Medicine

1900 S National Ave.

Suite 2900

Springfield MO 65804

Phone: 417-820-3715

Provides high-risk obstetrics including first trimester and sequential screening, and prenatal diagnosis.

[University of Missouri Prenatal Diagnosis Program](#)

Columbia, MO

Phone: 573-882-8934

Provides diagnosis, treatment, management, and genetic counseling services for pregnant women.



[Women's Health Center](#)

Washington University School of Medicine  
Center for Advanced Medicine  
St. Louis, MO  
Phone: 314-454-7552

Provides diagnosis, treatment, management, and genetic counseling services for preconceptual and pregnant women.

**MULTIDISCIPLINARY GENETIC CLINICS FOR SPECIFIC DISORDERS**

**Autism Clinic**

[The Thompson Center for Autism and Neurodevelopmental Disorders](#)

University of Missouri  
Columbia, MO  
Phone: 573-882-6081

Provides comprehensive services for individuals with autism of all ages. Specialist from genetics, developmental pediatrics, psychology, speech and neurology attend the clinic.

**Cleft Palate Clinic**

[Cleft Palate Clinic](#)

Children's Mercy Hospital  
Kansas City, MO  
Phone: 816 234 3771

Provides diagnostic and surgical management services provided by a team of experts in craniofacial disorders.

**Craniofacial Clinics**

[Craniofacial Clinic](#)

University of Missouri  
Columbia, MO

Provides comprehensive services to children with craniofacial anomalies.

Craniofacial Clinic  
SSM Cardinal Glennon Children's Medical Center

St. Louis, MO  
Phone: 314-577-5639

Provides comprehensive services to children with craniofacial anomalies.

### **Dermatology Clinic**

#### [Dermatology Clinic](#)

Children's Mercy Hospital  
Kansas City, MO  
Phone: 816-234-3771

Provides diagnostic and management services from dermatologists, nurses, clinical genetics, and genetics counselors.

### **Down Syndrome Clinics**

#### [Down Syndrome Clinic](#)

Children's Mercy Hospital  
Kansas City, MO  
Phone: 816-234-3771

A multidisciplinary approach with services provided by pediatric/genetics, social work, occupational, speech, and physical therapies, audiology, developmental/behavioral pediatrics, and nutrition.

#### [Down Syndrome Center](#)

Washington University School of Medicine  
St. Louis Children's Hospital  
St. Louis, MO  
Phone: 314-454-6093

### **Fetal Alcohol Syndrome**

#### [Fetal Alcohol Syndrome Clinic](#)

University of Missouri  
Columbia, MO  
Phone: 800-645-6164 or 573-882-9731

Provides an evaluation and management of patients referred for Fetal Alcohol Syndrome (FAS) or diagnosed with FAS. A multidisciplinary clinic comprised of a clinical geneticist, a child psychologist, occupational therapist, and a family advocate.

### [Midwest Regional Fetal Alcohol Syndrome Training Center](#)

Trains health care providers in fetal alcohol syndrome recognition, diagnosis, treatment, and prevention in Arkansas, Illinois, Indiana, Iowa, Kansas Missouri, Nebraska, and Oklahoma.

### **Huntington's Disease Clinic**

Mid Missouri Huntington's Disease Program  
University of Missouri  
Columbia, MO

Provides comprehensive presymptomatic genetic testing protocol with evaluations by genetics, neurology, neuropsychological testing, and psychiatry.

### **Marfan Syndrome Clinic**

Washington University School of Medicine  
St. Louis Children's Hospital  
St. Louis, MO  
Phone: 314-454-6095

A diagnostic and management clinic for children who have or are suspected to have Marfan syndrome or other related connective tissue disorder.

### **Metabolic Clinics**

#### [University of Missouri](#)

Columbia, MO  
Phone: 573-884-5192

Provides metabolic diagnostic and management clinic for newborns, children, and adults.

#### [Metabolic Genetics Clinic](#)

Children's Mercy Hospital  
Kansas City, MO  
Phone: 816-234-3771

Provides metabolic diagnostic and management clinic for children. Includes patients identified by newborn screening.

Saint Louis University School of Medicine  
SSM Cardinal Glennon Children's Medical Center  
St. Louis, MO  
Phone: 314-577-5639

Provides metabolic diagnostic and management clinic for adults and children.

Washington University School of Medicine  
St. Louis Children's Hospital  
St. Louis, MO  
Phone: 314-454-6093

Provides metabolic diagnostic and management clinic for adults and children.

PKU Telehealth Clinics  
Cox South Medical Center Telehealth Clinic (University of Missouri)  
Cox South Medical Center  
Turner Center  
Springfield, MO  
Phone: 417-277-5619

Provides phenylketonuria (PKU) diagnostic and management clinic for children and adult patients with confirmed PKU.

### **Neurofibromatosis Clinics**

[Washington University School of Medicine](#)  
St. Louis Children's Hospital  
Phone: 314-454-6120

Neurofibromatosis Clinic  
Saint Louis University School of Medicine  
SSM Cardinal Glennon Children's Medical Center  
St. Louis, MO  
Phone: 314-454-6120

[Prader-Willi Syndrome Clinic](#)  
Children's Mercy Hospital  
Kansas City, MO  
Phone: 816-234-3771

## Local Resources

### [Down Syndrome Association of Greater St. Louis](#)

8420 Delmar Blvd., Suite 506  
St. Louis, MO 63124  
Phone: 314-961-2504

The Down Syndrome Association of Greater St. Louis mission is to benefit the lives of people with Down syndrome and their families through individual and family supports, information, public awareness and advocacy.

### [Down Syndrome Guild of Greater Kansas City](#)

10200 W. 75th Street, Suite 281  
Shawnee Mission, KS 66204  
Phone: 913-384-4848 or 913-384-9898 24-hour Information Line

The Down Syndrome Guild (DSG) of Greater Kansas City mission is to provide support and resources for individuals with Down syndrome and their families. DSG seeks to provide the entire community with information and education to broaden awareness and foster positive attitudes regarding people with Down syndrome.

### [Easter Seals](#)

Easter Seals provides services to children and adults with disabilities and other special needs, and support to their families.

Easter Seals Missouri  
Corporate Office  
[www.mo.easterseals.com](http://www.mo.easterseals.com)  
13975 Manchester Rd  
Manchester, MO 63011  
636-227-6030

St. Louis City, The Lodge  
[www.mo.easterseals.com](http://www.mo.easterseals.com)  
6918 Fyler  
St. Louis, MO 63139  
Phone: 314-644-6507

St. Louis City, Northrup  
[www.mo.easterseals.com](http://www.mo.easterseals.com)  
5025 Northrup  
St Louis, MO 63110  
Phone: 636-227-6030

Childgarden and Easter Seals and ARC Child Development Center

[www.mo.easterseals.com](http://www.mo.easterseals.com)

4150 Laclede Ave.

St. Louis, MO 63108

Phone: 314-531-8148

Jefferson City, Easter Seals Adult Day Services

[www.mo.easterseals.com](http://www.mo.easterseals.com)

1719 Southridge

Jefferson City, MO 65109

Phone: 573-761-7300

Columbia, Easter Seals Child Development Center

[www.mo.easterseals.com](http://www.mo.easterseals.com)

3804 Santiago Drive

Columbia, MO 65203

Phone: 573-449-6783

### **Center for Innovations in Education (CISE)**

205 London Hall

Columbia, MO 65211-2390

Phone: 573-884-7275

Center for Innovations in Education provides professional development services and resources for those who help to ensure that all learners achieve his/her potential. Services include an on-line catalog of medical resources, including dictionaries (good resource for parents).

### **March of Dimes**

Missouri March of Dimes Chapters

Greater Missouri

Phone: 314-646-8601

Kansas City Division

Phone: 816-561-0175

March of Dimes researchers, volunteers, educators, outreach workers, and advocates work together to give all babies a fighting chance against the threats to their health: prematurity, birth defects, and low birthweight.

### **Pujols Family Foundation**

111 Westport Plaza, Suite 255

St. Louis, MO 63146

Phone: 314-878-2105

The Pujols Family Foundation promotes awareness, provides hope and meets the tangible needs for families and children who live with Down syndrome; to provide extraordinary experiences for children with disabilities and/or life threatening illnesses; and to improve the standard of living and quality of life for impoverished children in the Dominican Republic through education, medical relief, and tangible goods.

### **St. Louis Arc**

1816 Lackland Hill Parkway

Suite 200

St. Louis, MO 63146

Phone: 314 569-2211

The mission of St. Louis Arc is to provide the highest quality services to help people with developmental disabilities, and their families, achieve their goals. Services provided are designed to maximize choice and to support people as they build quality lives within the St. Louis community.

### **St. Louis Children's Hospital**

Search the online "Healthinfo" library, a St. Louis Children's Hospital's comprehensive resource on all things related to your child's health and safety. Enter your topic of interest in the search box, or visit their individual sections listed below on their web page.

## **National Associations**

### **March of Dimes**

1275 Mamaroneck Avenue

White Plains, NY 10605

Phone: 914-997-4488

March of Dimes researchers, volunteers, educators, outreach workers, and advocates work together to give all babies a fighting chance against the threats to their health: prematurity, birth defects, and low birthweight.

### **National Birth Defects Prevention Network**

The mission of the National Birth Defects Prevention Network (NBDPN) is to establish and maintain a national network of state and population-based programs for birth defects surveillance and research to assess the impact of birth defects upon children, families, and health care; to identify factors that can be used to develop primary prevention strategies; and to assist families and their providers in secondary disabilities prevention. For resources specific to NBDPN go to <http://www.nbdpn.org/current/resources/links.html>

### **National Down Syndrome Congress (NDSC)**

Phone: 800-232-NDSC

The mission of the NDSC is to provide information, advocacy, and support concerning all aspects of life for individuals with Down syndrome. This web site includes important information on Down syndrome – facts, concepts and philosophies that all who are concerned about people with Down syndrome need to know and use. This includes a New Parent Package; a collection of materials refined over the years to provide new and expectant parents with an initial understanding of the challenges – and joys – of raising a child with Down syndrome. There is also a wide array of current, expert articles, recommended reading and answers to the most frequently asked questions regarding Down syndrome.

### **National Down Syndrome Society (NDSS)**

The mission of the National Down Syndrome Society is to benefit people with Down syndrome and their families through national leadership in education, research and advocacy. The National Down Syndrome Society envisions a world in which all people with Down syndrome have the opportunity to realize their life aspirations. NDSS is committed to being the national leader in enhancing the quality of life, and realizing the potential of all people with Down syndrome.

### **Spina Bifida Association**

4590 MacArthur Boulevard, NW  
Washington, DC 20007  
Phone: 800-621-3141

The Spina Bifida Association of America (SBAA) addresses the specific needs of the spina bifida community and serves as the national representative of almost 60 chapters. SBAA's efforts benefit thousands of infants, children, adults, parents, and professionals each year.



### **Easter Seals**

230 West Monroe Street, Suite 1800

Chicago, IL 60606

Phone: 800-221-6872

Easter Seals provides services to children and adults with disabilities and other special needs, and support to their families.

### **Genetic Alliance**

4301 Connecticut Ave. NW

Suite 404

Washington, DC 20008-2369

Phone: 202-966-8553

The Genetic Alliance is a coalition of more than 600 advocacy organizations serving 25 million people affected by 1000 conditions.

## **Federal Resources**

### **Emergency Medical Services for Children**

The Emergency Medical Services for Children is a national initiative designed to reduce child and youth disability and death due to severe illness and injury.

### **MedLinePlus**

MedLinePlus is a service of the U.S. National Library of Medicine and the National Institutes of Health.

MedLinePlus directs you to information to help answer health questions. It brings together authoritative information from the National Library of Medicine, the National Institutes of Health (NIH), and other government agencies and health-related organizations. Preformulated MEDLINE searches are included in MedLinePlus and give easy access to medical journal articles.

### **National Center on Birth Defects and Developmental Disabilities**

The mission of the National Center on Birth Defects and Developmental Disabilities (NCBDDD) promotes the health of babies, children, and adults, and enhances the potential for full, productive living. This work includes identifying the causes of and preventing birth defects and developmental disabilities, helping children to develop and reach their full potential, and promoting health and well-being among people of all ages with disabilities.

### **National Institutes of Health**

The National Institutes of Health (NIH), a part of the U.S. Department of Health and Human Services, is the primary federal agency for conducting and supporting medical research. It helps lead the way toward important medical discoveries that improve people's health and save lives. NIH scientists investigate ways to prevent disease as well as the causes, treatments, and even cures for common and rare diseases. Composed of 27 Institutes and Centers, the NIH provides leadership and financial support to researchers in every state and throughout the world.

### **National Institute of Neurological Disorders and Stroke**

The mission of the National Institute of Neurological Disorders and Stroke (NINDS) is to reduce the burden of neurological disease - a burden borne by every age group, by every segment of society, by people all over the world.

### **National Library of Medicine**

A part of the United States National Library of Medicine - is a good resource of additional information if there is a known syndrome diagnosed and more resources are needed.

## **General National Resources**

### **Anencephaly Support Foundation**

The purpose of the Anencephaly Support Foundation is to help parents who wish to continue these pregnancies, and help these parents examine the reasons why they believe carrying a child with anencephaly can be a fulfilling decision.

### **Living with Trisomy 13**

The Living with Trisomy 13 site is for those families who have had a child diagnosed with Trisomy 13 – Patau Syndrome. Whether they are: on the prenatal journey, have a child living presently, or have a child who has died and are still grieving.

### **The Arc of the United States**

The Arc of the United States advocates for the rights and full participation of all children and adults with intellectual and developmental disabilities. Together with their network of members and affiliated chapters, they improve systems of supports and services; connect families; inspire communities, and influence public policy.

### **National Center for Hearing Assessment and Management**

2880 Old Main Hill  
Logan, UT 84322  
Phone: 435-797-3584

The National Center for Hearing Assessment and Management's mission is to have all infants and toddlers with hearing loss identified as early as possible and provided with timely and appropriate audiological, educational, and medical intervention.

### **National Organization for Rare Disorders (NORD)**

55 Kenosia Avenue  
P. O. Box 1968  
Danbury, CT 06813-1968  
Phone: 203-744-0100 or 800-999-6673 (voicemail only)  
TDD Number: 203-797-9590

The National Organization for Rare Disorders (NORD) is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.

### **Stickler Involved People (SIP)**

Stickler Involved People (SIP) is a not-for-profit organization whose mission is to educate and give support to all those affected by Stickler syndrome. Stickler syndrome is a connective tissue disorder, a genetic malfunction in the tissue that connects bones, eyes, and ears. This disorder is associated with problems of vision, hearing, bone and joint, facial and cleft palate.

### **Support Organization For Trisomy 18, 13 and Related disorders**

The Support Organization for Trisomy (SOFT) is a network of families and professionals dedicated to providing support and understanding to families involved in the issues and decisions surrounding the diagnosis and care in Trisomy 18, 13 and related chromosomal disorders. Support is provided during prenatal diagnosis, the child's life and after the child's passing. SOFT is committed to respect a family's personal decision - in alliance with a parent / professional partnership.

## Other Resources

### [2007 Toll-Free Numbers for Health Information](#)

These selected toll-free numbers for organizations provide health-related information, education, and support. These organizations do NOT diagnose or recommend treatment for any disease.

### [Case Management Resource Guide](#)

The Case Management Resource Guide contains 1677 records with web links on almost every possible medical condition, including many toll free numbers to call for additional information. This is part of the Dorland Health Care Information Site - and a good resource if a family is relocating to another state (in addition to contact information for the local agencies).

### [Center for Children with Special Needs Care Notebook](#)

The Care Notebook is an organizer for families who have children with special health care needs. Families use Care Notebooks to keep track of important information about their child's health and care. This makes it easier to find and share key information with their child's care team.

### [eMedicine from Web MD](#)

eMedicine comprises the largest and most current Clinical Knowledge Base available to physicians and other healthcare professionals. Comprehensive medical textbook information is available for all clinical fields.

### [Family Village](#)

Complete library for disability related resources.

### [Health A-Z](#)

Health A-Z is a helpful site with information from conception to seniors. It includes an "ask our expert" column that includes a pediatrician, nurse, and nutritionist for general questions and concerns.

### [Healthfinder](#)

Site includes medical information that is easy to understand and covers a wide variety of subjects. It also includes a directory to find other agencies, clearinghouses, and resources for additional information.

### **[Internet Resource for Special Children](#)**

The Internet Resource for Special Children includes a variety of resource links.

### **[Med Help International](#)**

Search alpha list for additional information on health topics.

### **[Nemours](#)**

Nemours mission is to provide leadership, institutions, and services to restore and improve the health of children through care and programs not readily available, with one high standard of quality and distinction regardless of the recipient's financial status.

### **[U Seek U Find Medical Resources](#)**

U Seek U Find Medical Resources contains Medical Resources, Medical Dictionaries, Databases, Encyclopedias, and Glossaries and is a good resource for parents.

### **[V.I. Guide](#)**

V.I. Guide contains specific information for assistive products for blind children and adults.